Listening to the parent voice to inform person-centred neonatal care.

Abstract

Family integrated care (FIC), where parents are an integral part of their baby's care and decision-making can enhance parental involvement and empowerment, contributing to decreased parental separation and stress. It follows that parents can also be a central part of neonatal education for staff in the neonatal speciality. This paper focuses on what students and staff can learn from parents about what they feel is important to make their experience better. A narrative, interpretive approach was undertaken to collect and analyse parent interview narratives. A specific question was posed to a purposive sample of parents who have had premature babies about what health professionals can learn from them. Thematic analysis revealed five key themes relating to the importance of: communicating; listening; empathising; acknowledging (the parent's role); realising (what matters to parents). These elements were incorporated into a framework named by the mnemonic, 'CLEAR'. This highlights what parents want staff to be cognisant of when caring for them and their babies. Learning from the parents in our care enables a greater understanding of their experiences at difficult and challenging times. Having a deeper understanding of parents' experiences can contribute to enhanced empathic learning.

KEY WORDS

Parent experience / Neonatal education / Family-integrated learning / Narrative inquiry

INTRODUCTION

Parents whose babies are admitted to neonatal care are subject to a variety of stresses that increase their risk of suffering emotional distress and anxiety. This can adversely impact the bonding process, which in turn can lead to worse outcomes for both the baby and parents (Hall et al, 2016). It is well documented how important family integrated care (FIC) is to enhance parental involvement, empowerment and confidence (D'Agata & McGrath, 2016; Aloysius et al, 2018a; Banerjee et al, 2018; O'Brien et al, 2018) contributing to minimising the psychological impact on families of having a premature baby on a neonatal unit (Jiang et al, 2014). From an education perspective, it is therefore essential that children's nursing and/or midwifery students as well as new staff in this field, are taught about the emotional side of neonatal care to ensure they understand how to offer more sensitive and humanistic care to parents. This person-centred approach can be seen as acknowledging the notion of a holistic approach to care that incorporates a person's context and individual preferences and beliefs, not limited to only the patient but to families and caregivers too (Santana et al., 2018).

In line with a person-centred philosophy, the FIC model highlights how parents should be regarded as equal members of the neonatal unit multidisciplinary team (Read & Rattenbury, 2018). It follows that parents are a source of valuable information for students and staff working in neonatal care to learn from. Such parent informed teaching is congruent with the principles of FIC. In the context of this study, that is education where staff and parents are equitable partners and mutually learn from each other.

This paper reports on one component of a larger study that explored parent narratives about their neonatal experience, now leading to the development of digital storytelling learning resources informed by said parents. In this main study, parents were interviewed to collect

their stories about their experience of having a premature baby through the neonatal unit and beyond and comprised two overarching components: Firstly, what the parents experienced through their neonatal trajectory to inform learning resources using their narratives is to be published separately (pending). The methodological approach to story creation used in this part of the study has also been reported previously (Petty et al, 2018). The second component, and the focus of this paper yet to be reported, is an exploration of what learning students and staff can draw from the experiences of parents themselves. This stage of the main study focused on parent responses to a key question asking their views of what staff can learn from them. The onus is so often and most frequently on parents learning from health professionals, but this perspective focuses on the reciprocal perspective: i.e. what can students and staff learn from parents? Due to recent emergence of the importance of family-integrated care, it was deemed pertinent to report on this specific area as a separate entity.

METHODS

Design

The study was designed within a narrative, interpretive paradigm which seeks to explore and make sense of phenomena and personal experience (Clandinin and Connelly, 2000), in this case the narratives of parents to enable practitioners to understand what it is like to live through a period of neonatal care with their premature baby. It is documented that people come to understand and give meaning to their lives through story (Andrews et al, 2008). The purpose of interpretive work in the context of this study is to assign meaning to parent narratives to acquire knowledge about their experience to learn from.

Participants

In relation to the participants, the aim was to obtain a variety of different experiences and stories to use in a learning and teaching capacity. Purposive sampling, commonly used in qualitative research, was employed for this study where participants are selected based on specific characteristics. In this case, sampling was defined to parents who had had a premature baby (born before thirty-seven weeks), had spent more than a week receiving neonatal care and who had been discharged home in the preceding ten years. The inclusion criteria were purposefully broad and did not seek to select specific characteristics. Being too restrictive would have potentially prevented a varying range of experiences and stories. For the same reason, exclusion criteria were limited to parents whose babies were born after thirty-seven weeks gestation and had spent less than a week in neonatal care.

Parents were accessed by requesting volunteers through a key gatekeeper linked to a UK parent support charity who disseminated the recruitment call nationally using their established email contact database. Once volunteers came forward, the gatekeeper's role was to forward their details to the first author to make contact with them. The volunteer approach meant the researchers were not in control of the specific parent characteristics of those who came forward to tell their story, such as age, gender or ethnicity, nor the number who would come forward. All parents who volunteered were interviewed for their story and so the researchers did not know who had declined to take part. The decision was made between the authors to continue recruitment until they had agreed that sufficient data had been collected that would enable a range of rich narratives to work with, and inform others.

Overall, twenty-three participants were recruited across a range of areas within England. The participant group comprised sixteen mothers, one father and three mother-father pairs

(interviewed together) who were parents to a total of twenty-seven premature babies. Details of participants are outlined in Table 1.

Twenty interviews were arranged by the first author at a convenient time with the parents in their own home or an agreed, private location. Each parent was given a participant information sheet explaining the study and that their narratives would be used for teaching and learning purposes. As well as written information, informed consent was confirmed prior to all the interviews enabling further verbal information to further clarify and address queries prior to the interview.

For the main study, the interviews were narrative in nature which is a way to collect open participant stories without a fixed agenda where those being interviewed have the control over the pace, direction and content (Anderson & Kirkpatrick, 2016). This was instrumental in obtaining stories for learning, a main study objective. Therefore, parents were asked to tell their story about the experience in neonatal care through to the current day after discharge. However, as the objective of this specific component of the main study was to explore parent perspectives on what staff can learn from them, one specific question was asked at the close of all the interviews: ‘*’what can health professionals learn from you as parents, and your experiences in neonatal care*?’’ This added a semi-structured component to the narrative interviews.

The interviews were undertaken by the first author and they lasted between a range of between sixty (minimum) and one hundred and five (maximum) minutes. They were audio-recorded digitally and manually transcribed, also by the first author to enable immersion in the acquired data and familiarisation with emerging themes. Transcripts were sent to and

verified by the parents themselves in line with ‘member checking’ a strategy that addresses the co-constructed nature of knowledge by providing participants with the opportunity to add to and engage with the interpreted interview data (Birt et al, 2016), a strategy used to optimise trustworthiness of narrative data within qualitative research.

Ethical considerations

The study design and procedures were approved by the first author’s Higher Education Institute Ethics Committee; Protocol number: aEDU/PGR/UH/02074. This included guarantees that parents would give informed consent prior to any interview and that all participant data would be anonymised, stored securely and confidentially in line with current data protection laws. Informed consent was also required, not only for the interview to be carried out and recorded but for permission to use interview narrative extracts for teaching purposes. The ethics application gave assurances that interviews would be stopped if emotional distress was encountered by the parents, since reliving challenging experiences potentially could have triggered strong emotions.

Table 1:Participant details

Participant details		Number
Parent(s) interviewed	Mother	16
	Father	1
	Mother & father together	3
Age of child at interview	1-2 years	6
	2-4 years	8
	4-6 years	2
	6-8 years	4
	8-10 years	5
	Died	2
Gender of child	Male	14
	Female	13
Gestation born	24-26 weeks	13
	26-28 weeks	3
	28-30 weeks	6
	30-32 weeks	5
Birthweight	500-750 grammes	12
	750 -1000 grammes	5
	1000-1500 grammes	10
Order of birth	1st child	18
	2nd child	6
	3rd child	2
	4th child	1
Singleton or multiple birth	Singleton	25
	Twin	2

Analysis

Thematic analysis as proposed by Braun and Clarke (2014) was chosen to explore parents' experiences which involved familiarising with the narratives, transcribing, reading and noting down initial ideas followed by coding of identified themes, culminating in a final review and categorisation of main themes for naming and reporting. Due to its flexible approach that can be modified for the needs of many studies, thematic analysis can offer provision of rich and detailed analysis of data (King, 2004 cited by Nowell et al (2017). Key themes and sub themes were identified by this approach, in response to the abovementioned key question. The analysis was primarily carried out by the first author, with the second and third authors ensuring that they agreed with the approach and reviewing data interpretation throughout the whole study. The researchers met regularly to confirm verification of the emerging themes, again a further strategy for enhancing trustworthiness and rigour in qualitative data (Cope, 2014). The identified themes that emerged from the key question about what health professionals can learn from parents will now be discussed.

RESULTS

Overall, responses to the question about what health professionals can learn from parents revealed many areas in relation to how the parents wanted to be treated and what they felt was important for staff to be cognisant of, when caring for them and their babies. The themes for learning identified by parents are outlined in Table 2. Five broad areas were identified regarding what parents see as important in their care: namely, the importance of; communication; listening to the parent voice; empathy and emotional care; acknowledgement of the parent role; and the need for staff to realise and understand both parents' needs and what matters to them for a positive experience of neonatal care.

Table 2: Themes identified from parent narratives *'What can health professionals learn from you as parents, and your experiences in neonatal care?''* ***It is important for staff to……***
COMMUNICATE WITH US
<u>Communication includes:</u> How What When Who
LISTEN TO US
<u>Listening includes:</u> Being genuinely heard Parents having a voice Considering parents intuitive knowledge
EMPATHISE WITH US
<u>Empathising includes:</u> Delivering emotionally intelligent care Being sensitive care to the whole family Instilling humanistic values in care
ACKNOWLEDGE US AS PARENTS
<u>Acknowledging includes:</u> Including parents as part of the team Acknowledging the parenting role Facilitating parent involvement in care
REALISE OUR NEEDS AND WHAT IS IMPORTANT TO US
<u>Realising includes:</u> Understanding what is important to parents Enhancing the parent experience Delivering person-centred care

'Communicate with us'

Parents identified the importance of full, open, honest information as early as possible and which is consistent in the face of potential differences between neonatal units and staff members. The birth of a premature baby clearly put the parents under much emotional strain and effective communication is seen as a main factor contributing to making the parent's

experience better. Communication is a frequently occurring area highlighted in other research that has explored parents' experiences in neonatal care. Whilst it is not always possible to prepare for the birth, effective communication is consistently highlighted as vital to reduce the impact of stress (Cockcroft, 2012).

''You need to be able to communicate properly with us, you must be careful how you say things…… be honest and accurate but sensitive''

''I would say to any health professional, think about what you say and how you say it''

''Consistency is so important so that we don't get confused''

''Listen to us''

Being listened to in a genuine and consistent manner was also very important to many of the parents; they wanted to have a voice and be taken seriously when it came to identifying changes in their baby's condition and decisions about care including strong beliefs some parents held about how early care impacts on future outcomes of their babies. Another paper highlighted the need for neonatal nurses and other health professionals to be aware of the different views, experiences and needs of parents parenting while their baby stays in hospital (Mendizabal-Espinosa & Podsiadly, 2018).

''We must be listened to''

''Our voice is so important… our views must be taken on board''

''Empathise with us''

Empathic, emotionally sensitive care is of significant value to parents during an often difficult and challenging period, as demonstrated in this study. The neonatal care experience poses many emotional challenges for families, parents and siblings that require staff to be mindful of and to offer a compassionate approach to care while maintaining emotional intelligence. This concurs with a study that found empathetic communication as one aspect of

staff communication was effective in reducing parental stress, providing evidence for the need to involve parents in an emotionally sensitive way from the beginning of their baby's stay in the neonatal unit (Enke et al, 2017).

''Staff should try and have empathy and understand, the emotional side of it all''
''These small things make such a difference''
''Consider our emotional health ... I was depressed, and no-one noticed''.
''As a dad, I felt I didn't have a role and I was emotional too''

''Acknowledge us as parents''

Values-based care involving trust along with the recognition of, and respect for, parents as equal partners, are regarded as important for parents to feel their emotional needs are being addressed properly. Parents also want to have acknowledgement and recognition of their role as a parent, to feel empowered and supported to engage in activities that make them feel like a parent and to be able to bond as a family. It has been shown that parents who partner with nurses and the health care team are better able to assume their roles as parents and overcoming the stress associated with neonatal care. This is possible with creative partnerships that empower parents to build self-confidence and competence in their role (Fleck, 2016). Enabling the parenting role is vital and requires careful support and nurturing (Vazquez & Cong, 2014)

''After that, I felt empowered and I felt I could voice what I wanted''
''You must include us from the start''
''We are the parents; we are, or should be part of the team''

''Realise what is important to us''

Finally, parents want nurses and health professionals to realise and come to a genuine understanding of what is important for true person-centred, family focused care. Some parents verbalised the need for staff training in this area to ensure that parents' emotional needs are understood and considered throughout their neonatal journey. Some referred to specific care practices that appeared to make their experience a more positive one such as facilitation of closeness by skin-to-skin, breast-feeding and developmentally supportive care along with being involved in the care of their babies. Again, the need for staff to realise how significant such practices were from the parent's perspective was seen as vital.

''Try and give us more support at difficult times''
''It is so important for staff to realise and understand what we need at such difficult times''
''These things (skin-to-skin, developmental care) are so important and help us all''

DISCUSSION

Parents in this study identified a range of issues that contributed to making their care experience both better and worse. It is clear that the benefits of integrating the family in care cannot be disputed (O'Brien et al, 2018) and has the potential to improve short and long-term infant and family outcomes such as reduction in parental stress. Further work concurs with these findings proposing that the implementation of interventions focused on reducing parental stress is crucial, to make the parent experience a more positive one. This can then diminish negative consequences in family emotional health (Baía et al., 2016). Family integrated care is a key example of a strategy to ensure this occurs and it is vital to contribute new knowledge about approaches to active involvement of parents in the care of their baby on neonatal units (Skene et al, 2016).

It can be argued that the themes identified in this study are not necessarily new given the cited research thus far and the similar findings in relation to parental stress. This current study does provide though, further support to add weight to any recommendations needed to improve the parent experience. In addition, what requires attention is how to educate about these key themes and integrate knowledge gained from the parents' experience into the essential learning for all staff who work in this specialised and complex area. It is acknowledged that neonatal specific education must include care which promotes positive infant development along with family emotional stability aimed at enhancing parent–infant relationships (Picker Europe, 2015). Such core skills and knowledge must form the basis of a developmental and family-based approach to care which must be taught to those learning within this field (Turrill, 2014) .

Based on these findings, in conjunction with other key literature referred to, a parent-informed framework outlining what students and staff should know about the experience and needs of parents has been developed by the first author, depicted in Figure 1. This is applicable globally in that wherever health professionals and students work and learn, these principles can be applied, independent of available resources. It is important that the wording of the framework is written from the parent perspective. Moreover, specific examples of 'CLEAR' strategies informed by the parents themselves can be seen in Table 3. These align with research that has led to recommendations for supporting parental roles as caregivers of their babies in the neonatal unit, facilitating neonatal staff commitment to true family centred / integrated care and creating policies that support these types of care models (Craig et al., 2015; Franck et al, 2017).

Figure 1: The 'C L E A R' Approach to understanding what is important to parents

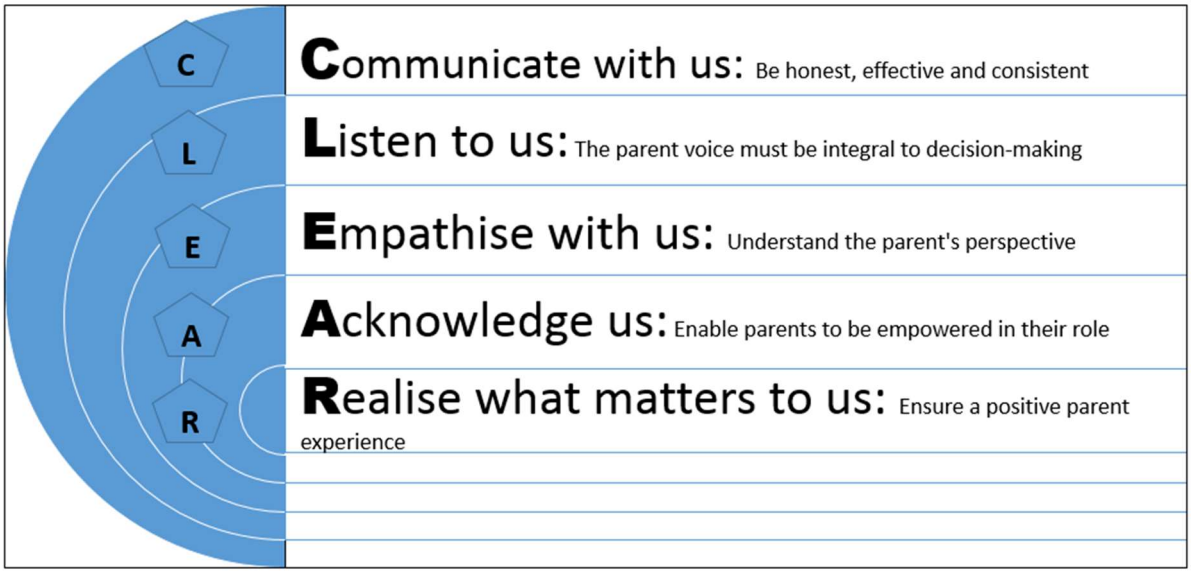

Table 3: Suggested 'CLEAR' Strategies		
COMMUNICATE WITH US		
C	**What parents said** Give open and honest information consistently throughout the neonatal unit stay, starting as early as possible.	**Examples of strategies** • Tailor / individualise information needs for parents • Consistent and high-quality information as well as a supportive education programme • Train all staff in effective communication skills
LISTEN TO US		
L	**What parents said** Being properly listened to and having a voice enables parents to feel that they have a role in their baby's care. Parents feel that they have vital, intuitive knowledge that needs to be taken seriously.	**Examples of strategies** • Providing parents with the opportunity to participate in multidisciplinary rounds • Parents' opinions to be heard by regular discussions • Planned, scheduled meetings based on parent reflection (consider 'Guided Family centred care' – GFCC (Weis et al, 2015) • Involve parents in decision-making as part of the multi-disciplinary team
EMPATHISE WITH US		
E	**What parents said** It is essential to give parents emotionally intelligent care. This includes the instillation of values such as honesty and trust.	**Examples of strategies** • 'Psychosocial' strategies such as implementing staff-parent mentors, 24/7 parent presence and facilitation of parent peer support groups.

	The whole family including the father and siblings must be cared for emotionally and practically.	• Provide psychological support for parents when required involving other professionals, charity links or volunteers in key parent support / pastoral care roles. Consider employing mental health practitioners / psychologists / counsellors. • Provide key support for discharge and follow up. • Screen for and normalise emotional distress. • Offer relaxation exercises (Fotiou et al., 2016)
	ACKNOWLEDGE US AS PARENTS	
A	**What parents said** Parents should be a vital part of the team. The importance of the parenting role must be acknowledged. The need to be involved in their baby's care contributes greatly to feeling empowered and having an essential role.	**Examples of strategies** • Family-Integrated Care (FIC) (Lee & O'Brien, 2018) • Parent involvement / participation in care (Ottosson & Lantz, 2017) • Include the whole family; fathers (Stefana et al, 2018), siblings (Morrison & Gullon-Rivera, 2017) and grandparents in care and visitation policies. • Educate parents and empower them to be "experts" in their baby's care and participate in the care team as equal partners (Platonos et al, 2018) • Provision of a 'coherent' environment (Thomson et al., 2013) conducive to FIC: e.g.: rooms for relaxation, peer contact and 'rooming in', kitchen and shower facilities, 24-hour parental access with no limitations during shift changes or rounds.
	REALISE WHAT IS IMPORTANT TO US	
R	**What parents said** Staff must realise and understand what parents find important in making their neonatal experience a more positive one. Staff should be cognisant with not only the physical care of the baby but also the emotional and psychosocial needs of the parents / family to ensure care is truly person-centred.	**Examples of strategies** • Education and training for students and staff in the principles and importance of family centred care (Roué et al., 2017) and family-integrated care (see above). • Training is imperative for staff in the specific care interventions areas identified as having a positive impact by parents: e.g. effective pain & stress management, facilitation of breast-feeding and lactation support, skin-to-skin contact, developmental care and the more difficult ones relating to emotional care; e.g. breaking bad news (Macdonell et al., 2015)

Implications for practice

It is clear from the findings of this study that there are important implications for future practice relating to neonatal education. Successful implementation of FIC in the first instance

is essential, to support the shift in focus on delivering care to working with parents as part of the unit team and treating them as equal and active members in the care of their baby. Education should therefore also include an understanding of the parent experience informed by parents themselves to enable sensitive and effective communication required for partnership working (Aloysius et al, 2018b; Hall et al, 2016) and for the approach to care to be truly integrated and person-centred (Weis et al., 2015). Humanistic care should meaningfully align and be tailored to parents' needs to achieve and promote positive well-being and emotional health for them (Thomson et al, 2013). If learners and staff receive education on the psychoemotional needs of parents, as identified by the parents in this study, knowledge relating to the variables associated with stress can then be used to provide better supportive emotional care for parents (Turner et al, 2015; Baía et al., 2016) and a more empathic workforce.

Limitations

Finally, the limitations of the study need acknowledging. The study was undertaken within the interpretivist paradigm and various confines can be allied with this approach, relating to the subjective nature of the data and the interpreted meanings. However, qualitative work of this nature does not aim to generalise; rather the intention is to understand individual experience. In addition, strategies to optimise trustworthiness of the data were employed such as referring the original transcripts back to the parents themselves undertaken to verify the interpretations of their narratives and taking a reflexive approach to ensure transparency of data analysis and reporting, an essential part of qualitative research (Landy et al, 2016).
In addition, certain factors that could have potentially influenced the reported experience of parents; for example, parent narratives were obtained from a variety of time frames within a period of ten years. A long time-frame could have influenced the ability to recall events and

required consideration as a possible confounding factor. Indeed, practice in some areas has changed during this time and would have possibly impacted on the parents' experiences. However, the study was not comparing this issue. Moreover, difficulties with recall was not found to be the case. While the potential for recall bias needed considering, the parents in the study, even those whose children were now older than 5 years old, were able to recount their journey through neonatal care lucidly and freely, often stating that this was a valuable and cathartic process. Overall, common themes are revealed throughout the whole dataset regardless of these factors and no discernible differences were found while at the same time, each report of experience was unique to that parent(s).

Another area of consideration is the nature of recruitment; ability to control the characteristics of those who came forward was limited, due to the sampling being on a volunteer basis. This type of recruitment therefore can limit the spread and range of respondents required (Barbour, 2001) across gender and ethnic groups. Most parent participants in this study were mothers of Caucasian ethnicity and so were not representative of a range of different backgrounds. Further exploration of parental perspectives, embracing more fathers and those from more diverse cultural and ethnic backgrounds would be useful to reflect a wider range of parents who have had premature babies in the neonatal unit.

Conclusion

The findings of this study generate important insights into what parents need, to feel emotionally close to their babies and supported adequately. This knowledge contributes to an increased awareness of how to support parents of premature babies to form positive relationships with their babies and to improve their experience. Students and health care staff should create a climate where parents' emotions and needs are individually supported

(Flacking et al, 2016). One of the best ways we can create such empathic students and staff is to have them listen to the perspectives and work within a framework informed by parents themselves, here presented as the CLEAR approach. Learning from the parents in our care enables a greater understanding of their experiences at difficult and challenging times. Having a deeper appreciation of parents' experiences can contribute to enhanced empathic learning. In the future, designing learning resources that are genuinely informed by the parents themselves can ensure that we can better meet the emotional needs of parents so that neonatal education is truly informed by parents and authentically person centred.

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